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Observatoire social européen

paper

Why, in almost all countries, was residential care for older people so badly affected by COVID-19?



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Referring to this publication: Declercq, A., de Stampa, M., Geffen, L., Heckman, G., Hirdes, J., Finne-Soveri, H., Lum, T., Millar, N., Morris, J. N., Onder, G., Szczerbińska, K., Topinkova, E. and van Hout, H. (2020), Why, in almost all countries, was residential care for older people so badly affected by COVID-19?, OSE Working Paper Series, Opinion Paper No. 23, Brussels: European Social Observatory, 13 p.

Table of contents

Introduction.....	4
1. What happened?	5
1.1 Characteristics of the population	5
1.2 Primary focus on hospitals.....	6
1.3 The place of residential care for older persons in the health system.....	7
1.4 Monitoring quality in residential care	8
1.5 Positive effects	9
2. Why did this happen?.....	9
3. What now?.....	10
Bibliography.....	12

Introduction

As the world population ages, a larger number of older people need care. Community based services are promoted strongly across Europe and North America, as an alternative for care provision in institutional settings (Ilinca *et al.* 2015; Spasova *et al.* 2018). As a consequence, people stay at home longer, and the majority of older people in residential care need 24/7 care and have comorbidities (Onder *et al.* 2012). The number of beds in residential care per 100,000 inhabitants varies quite considerably. Belgium, Finland and Germany, for instance, have around 1,200 beds per 100,000 inhabitants, while Italy only has 376 and Poland 255 (1).

COVID-19 has proven to be a very challenging infection for frail older people. Its epidemiology has varied by area (both between and within countries), living situation, gender and clinical complications. It potentially strikes all adults, but its deadly effect is greatest among those who are 80 and older with comorbidities. Residents of residential care belong almost exclusively to that very high-risk group. A substantial percentage of them – 57.9% in care homes and 73% in residential care, according to Prince *et al.* (2014) – have dementia, which often makes managing their risk of exposure to the virus especially difficult.

During COVID-19, it became clear which parts of our health and social care systems function well, but also which parts are unsuited to the context of a global pandemic. In many countries, residential care for older people was one of the settings not prepared for a pandemic. In industrialised countries, the impact of COVID-19 has been most severe in residential care and for their residents. It is too early for a clear view of the total incidence and fatality rate, because testing strategies and methods of counting vary among countries (Gordon *et al.* 2020). While we need to be careful when interpreting these numbers, it is possible to identify a number of trends. In Belgium, which was severely hit by COVID-19, almost 6,200 persons – or 64.5% of all COVID-19 deaths – were people who lived in a nursing home. Of those, 14% died in a hospital, the others died in the nursing home (Sciensano 2020). In the United States, New York, New Jersey and Massachusetts were COVID-19 hotspots, with over half the deaths in residential care. Some countries (e.g. France and the Netherlands) did not report nursing home deaths in their initial COVID-19 communications (Fraser *et al.* 2020), but 72% of France's deaths were in these facilities (2); the equivalent number in the Netherlands was 46% (RIVM 2020).

International data from 19 countries show that, where there have been at least 100 deaths in total, the percentage of care home residents as a share of total deaths ranges from 24% in Hungary to 82% in Canada (Comas-Herrera *et al.* 2020). In Italy – with a low number of residential care beds – 31% of confirmed COVID-19 deaths still happened in residential care. This is about the same as in Germany, with many more residential care beds. The percentages

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1. https://gateway.euro.who.int/en/indicators/hfa_491-5101-number-of-nursing-and-elderly-home-beds/
 2. <https://www.santepubliquefrance.fr>

in France (46%) and Belgium (50%) are higher. Except for Hungary, only limited data are available from Eastern European countries. For example, the Czech Health Statistics Office does not collect these data. Local data show that in Prague, fewer than 10% of the facilities were affected and the proportion of nursing home deaths in the total death rate is about 20%. In Prague, as in Hong Kong, all recommended measures were quickly in place (Topinkova and Petrova 2020).

Statistics were reported very late in other countries, and so government responses were also delayed. The European Centre for Disease Prevention and Control (ECDC 2020) states that the lack of special surveillance systems and the differences in testing strategies and capacities among countries may have led to a significant under-ascertainment and under-reporting of cases, contributing to a general underestimation of the disease burden and mortality in residential care. Many deaths were preventable, the quality of life was severely affected and the working life of staff was filled with stress and risk of burn-out. One Canadian long-term care nurse stated that “the trauma from that will change you forever” (Welsh 2020).

1. What happened?

Residential care organisations are places where the majority of residents have many comorbidities and need high levels of care. They are not hospitals and do not require all the medical technology of hospitals. However, they do require sufficient staff with the expertise to protect residents from infectious diseases. Protecting the elderly from the virus is protecting the healthcare system, which protects us all (Lum 2020). In New Zealand, for example, there was a very early lockdown, strong immigration controls, and very good communication and public engagement. This included support for long-term care facilities, including the supply of personal protective equipment (Personal Protective Equipment or PPE) masks. Specific protection measures for older people in care were put in place very early, such as restricted visiting and detailed assessment of potential new residents before entry.

However, in most other countries, there are several reasons why nursing home residents were not protected from outbreaks, and why the homes had difficulty dealing with outbreaks. These have to do with the characteristics of the population, the primary focus on hospitals, the place of residential care for older persons in the health system and the lack of quality monitoring.

1.1 Characteristics of the population

Nursing home residents have very high levels of frailty, which place them at greater risk of adverse health outcomes in normal times, let alone in the midst of a global pandemic. The vast majority of the residents are in a nursing home because they have major underlying

comorbidities and they need help with everyday activities. This of course implies close contact with staff. In some countries, residents share rooms. During the daytime, residents are often brought together in a collective living room. Identifying which residents have an infection is very problematic, especially since the high prevalence of neurological conditions such as dementia may result in atypical COVID-19 clinical presentations, or even in the absence of evident signs or symptoms (ECDC 2020). For people with dementia, social distancing is difficult to maintain.

Older people in residential care show a high prevalence of chronic conditions that make them more vulnerable to catastrophic COVID-19 trajectories. Given the severity of these risks, it is all the more surprising that no immediate preventive action, such as limiting contacts with other people, or protective measures, such as the use of masks and other protective equipment, were taken for persons in long-term care. Also, the circumstances in which these people passed away were far from what is considered 'a good death' (Kehl 2006). They were not surrounded by their loved ones, often making it impossible to say a decent goodbye. In some cases, the equipment needed to make them comfortable – such as oxygen – was not available. Due to lack of time and training, advance care plans were often not in place, leaving staff and families in doubt as to whether the resident wanted to go to hospital or not. This resulted in situations where rushed decisions had to be made in the absence of knowledge about the person's preferences.

1.2 Primary focus on hospitals

In many countries (e.g. Belgium, France, Italy), the primary focus was on hospitals. Governments immediately worked with hospitals to postpone elective surgery, provided equipment, and organized mobile units. Residential care was an afterthought which only came to the public attention when catastrophic events began to unfold in individual homes. This has cost lives. The resources available to residential care were insufficient to be able to react swiftly to crises such as COVID-19 (Deusdad 2020). Staffing levels in residential care are notoriously low and staff are often not specialized in geriatric care. Close cooperation with geriatric and other specialty services is nonexistent in most residential care facilities. An interesting example, however, is the Czech Republic, where facilities were required to have a physician (usually a general practitioner) available via telemedicine or video, and skilled nursing facilities had a physician present within minutes if necessary (Topinkova and Petrova 2020).

Prevention should have been the first goal of all governments. When that was not achieved, full testing of residents and staff should have been a priority. When one resident at a care home in Cape Town, South Africa, died from COVID-19, an early testing strategy revealed 12 out of 185 residents and 32 out of 294 staff who tested positive; this allowed that facility to implement strict isolation and quarantining of all residents and staff, with no further deaths

from COVID-19 occurring in the facility. Testing, however, came late in many countries, as residential care was not a priority. Where guidelines to prevent infectious disease from spreading into residential care were released, they were typically available only in the late stages of the pandemic. Ontario, for example, only released them after a month. In Flanders (Belgium) the instructions from the relevant government agency changed 11 times between February 28 and April 28, and the number of pages increased from 2 to 48 (Declercq 2020).

In many instances, there were no coordinated efforts to test those with symptoms, isolate infected residents, quarantine their close contacts, and contain the outbreak once the disease entered the organisations. Furthermore, as many as 50% of staff working in long-term care carrying COVID-19 remained asymptomatic throughout the course of the infection, thus exacerbating the spread of infection to residents. For example, in Belgium, the overall number of asymptomatic cases among residents and staff was 75% of all cases that tested positive at residential facilities (ECDC 2020).

Other contributing factors may have been staff working in more than one facility, lack of PPE and lack of training and understanding of the disease at the beginning of the pandemic (ECDC 2020). Staff were unprepared and, at least in Belgium, had to learn about COVID-19 and what to do through online learning at home. Massachusetts had to quickly roll out infectious control training programmes. Given the chaotic state of public health responses to long-term care, staff cannot be blamed for ending up in the direst of circumstances.

1.3 The place of residential care for older persons in the health system

The third reason why residential homes had difficulty dealing with the outbreak is related to their place in national health care systems. COVID-19 clearly showed they were not a priority, in spite of their vulnerable population. Since experts have been predicting a pandemic for years, one would expect there to be plans and scenarios in place in case of such an event. But there was no plan, with few exceptions, such as Hong Kong and New Zealand. In Hong Kong, since SARS (a severe respiratory illness caused by a coronavirus) hit nursing home residents hard in 2003, most residential care organisations kept a one to three months' supply of PPE masks in stock in their homes. With this stock, they were able to get through the first months of COVID-19, and by then it was possible to restock (Chor 2020; Lum 2020). The Hong Kong Government also published its first infectious control guidelines for residential care in 2004, and required all residential care facilities to have a designated member of staff trained as Infectious Disease Control Officer to coordinate all infectious disease control measures. In Belgium, after H1N1 (also called the Mexican or swine flu), hospitals developed a 58-page crisis scenario. In residential care, a plan was developed, but was considered too expensive, with an average cost of 20,000 euro per facility (De Lepeleire 2020).

Many countries thus had not yet developed a protocol for how to deal with infected residents or staff, whether and how to use residential care for isolation and quarantine; neither was there a clear plan on whether or not to allow visitors, and how. The supply of masks and protective equipment for staff, and of oxygen and other equipment for comfort care for the residents, was insufficient. In case of an outbreak, residents were isolated either in their rooms or in cohorts of infected people within one unit. There was no isolation room equipped with negative air pressure and no designated disinfection area. Isolating residents in their rooms (Gordon *et al.* 2020) and not allowing them to have visitors are actions which tend to have detrimental effects on the quality of their life. Bringing infected residents together in a separate unit (cohort care) is probably a better solution but is also disruptive to the lives of the people involved.

People stay at home for as long as possible. Many governments in Western Europe have invested in home care services and often restrict access to residential care to those who need 24/7 care. This means that older persons moving to a nursing home are frail. While the resource needs of nursing home residents have increased, staffing levels have not followed suit. Consequently, residential care organisations often have to organise themselves in large units of 20 people or more. Staff may work in more than one unit, and thus encounter many residents. In times of a pandemic, these circumstances greatly increase the odds of contamination and spread of the disease. In most cases, staff did their utter best to provide good care, risking their own health and the health of their families, but felt little or no support from governments.

1.4 Monitoring quality in residential care

Regrettably, there are also residential care organisations where management and staff provided suboptimal care prior to the pandemic. To identify and address such deficiencies, governments need quality monitoring systems in place. For example, in Flanders (Belgium) an interim manager was sent to several facilities where managers were clearly unable to adequately deal with the situation during COVID. These monitoring systems should preferably be combined with comprehensive geriatric assessments and shared electronic resident files. These allow for early detection of changes in a person's condition. Belgium has a monitoring system and is implementing interRAI instruments (3) in all care for older people. Such a system is in place in Canada, with publicly available national reporting (4), but in other countries this type of quality monitoring is lacking. In some cases in Italy, residents were left alone in the facility, because the staff were either ill or scared, and no longer came to work.

3. InterRAI is a not-for-profit organisation of researchers and practitioners from over 35 countries. The interRAI instruments are compatible assessment instruments that can be used across health care sectors. For more information, see <https://www.interrai.org/> and www.belrai.org

4. Canadian Institute for Health Information: <https://yourhealthsystem.cihi.ca/hsp/?lang=en>

1.5 Positive effects

In the midst of all that went wrong, positive things also happened. Hospital doctors and nurses went to help in residential care facilities, as did home care nurses (this of course requires a lot of caution in order not to transmit the disease from one place to another). Integrated care, which was previously so difficult to arrange, all of a sudden happened overnight. In Flanders, preliminary analyses suggest that residential care organisations which collaborated more intensively with hospitals, and residential care organisations which had strong management, performed better (Goossens and Beel 2020). Citizens are shocked about what happened in residential care, and have become more aware of its needs. In France, it also became clear that integrated care was better able to meet residents' needs. Facilities that participated in an integrated care project stated they felt better supported by other community health services during COVID and that they more often shared geriatric protocols with hospitals.

2. Why did this happen?

The evidence presented above leaves us with a tough nut to crack: 'why did this happen?' Although it was very clear that frail older people were most vulnerable to COVID-19, the places with the highest concentration of this population were not prepared, did not have the necessary resources, had no plan, and became a focus of attention too late.

It is our contention that this is tragic evidence of how ageism taints the approach to care. Some espoused the view that these frail older people had had their life, and were no longer productive. The disregard for the role and the value of older people in society was used as a basis for downplaying the importance of the pandemic. For example, one Dutch columnist stated that it was irresponsible to let a lockdown endanger the economy and the future of young people in order to save dead wood ('dor hout' in Dutch), with which she meant older people (Zwagerman 2020). In policy briefs and political communications, the ageing society is associated with high costs and referred to as a problem for future generations. The media plays an important role in stereotyping and creating negative attitudes towards older people (Fraser *et al.* 2020).

The mere fact that especially – but not exclusively – older people are victims of COVID-19 may explain reluctance to comply with public health guidelines, by staying at home or closing shops and restaurants. Young people seem to feel more resistant, and therefore the argument for complying became "do this to protect your grandparents, even if you are not at risk." Guidelines exclusively developed for older people, such as a proposal in Belgium to restrict a second lockdown to people 65 and over, are patronizing and disregard the facts that younger

people can also get COVID, and that containing the epidemic is a responsibility of all citizens. A few countries, such as Singapore, Korea or Hong Kong, were able to protect their citizens, including nursing home residents, without a total lockdown. Their measures may have had a higher compliance rate and will be good references for other countries, helping them to prepare for future infectious disease outbreaks.

In our view, as a consequence of ageism, there is continuing lack of investment in residential care, along with negative representations of those organisations in the media. Society's undervaluation of and the lack of societal investment in residential care for older persons is at the root of the severe impact of COVID-19 on residential care. Their residents were not a priority for prevention, and the homes were not sufficiently financed or equipped to handle the outbreaks caused by the lack of preventive measures.

3. What now?

The biggest lesson learned from Hong Kong is that prevention is much more effective during a pandemic than curative measures. Knowing that the population in residential care is most vulnerable, we should be prepared. If we are prepared, we can effectively prevent COVID-19 or other infectious diseases from entering residential care, and can prevent a major outbreak within the nursing home if a virus does enter the home. To achieve this, residential care must be at the top of the priority list, together with home care and other places where vulnerable people are cared for.

But there is more: as a society, we must change the way we look at older people and at residential care. Perhaps COVID-19 will provide that turning point. Society may be ready for the residential care facility of the future – a warm and caring home for frail older people, with valued and trained staff who have sufficient clinical expertise to address residents' health needs. While it is true that most older people prefer to stay at home, and that deinstitutionalisation and investment in home care are positive developments, a significant group of very frail older people still need the 24/7 care that can only be provided in residential care. In order to achieve this, it is of utmost importance to invest in more and better qualified staff, protocols and a crisis scenario, and a stock of the necessary equipment. It is also vital to introduce good assessment systems such as interRAI, that make it possible to swiftly identify residents at higher risk or who show a change in their condition, and to monitor the quality of care. Pushing this to the top of the political agenda requires a change in our attitude to older people, and an awareness of the ageism that has influenced policies.

In 2019, a series of workshops on long-term care were organized by the European Commission's Directorate-General for Employment, Social Affairs and Inclusion (DG EMPL).

Several issues were discussed: unequal access to long term care, differences in structures and human resources (in terms of staffing ratio, qualifications, high turnover) between EU countries, and problems with affordability and funding, as well as quality of care. The challenges were defined, and some solutions and possible EU actions were proposed. It is time now to call on the European Commission to resume that discussion and make rapid progress on developing and implementing solutions to avoid this happening again in the future. The European Commission could, for instance, propose the drafting of guidelines for the Member States regarding residential care staffing. A Council Recommendation could be formulated regarding the need to invest in residential care alongside investments in home care. The older people of this era created and founded the European Union and supported the EU in its development. High quality care for these older people, and protection against the detrimental effects of pandemics such as COVID-19, should be high on the EU agenda.

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